



Nebraska Newborn Screening Program Policy on Protection and Release of Information



Authority

The authority for the following procedures for the release of information is found in the State Statute establishing the newborn screening requirements; Nebr. Rev. Stat. 71-519 (4), 71-520, 71-521, 71-522 (central data registry), and 71-524; and regulations Title 181, NAC 2, Screening of Infants for Metabolic Diseases; HIPAA requirements (45 CFR 164.512(b)) for public health surveillance programs; and, Nebraska State Statute 84-712.05 providing administrative authority. Under HIPAA, the program may exchange protected health information necessary with covered entities as required for conducting public health surveillance, investigations or interventions, and likewise covered entities may disclose to a public health authority, protected health information as required by the public health authority and as necessary for the care and treatment of the individual.

Program responsibility

The Newborn Screening Program is responsible for tracking and following up to verify that every newborn born in Nebraska receives an acceptable screen, and to verify that any out-of-range results receive appropriate repeat or confirmatory testing. This is part of the public health surveillance and tracking responsibility. In order to accomplish this, program personnel routinely communicate via phone, fax and/or letter with health care providers (individuals and hospitals) reported to be responsible for or involved with the care of the patient. Personally identifying health care information is shared between the program and the patient's health care provider's* or their designees to accomplish this assurance. (* Health care provider is defined as the patient's physician or other health professional caring for them, or the specimen submitter –usually a hospital and testing laboratories).

Exchange of information necessary to fulfill program responsibility

The health care provider identified to the program via the filter paper demographic information as the patient's physician may access the newborn screening results via the submitter of the specimen. In some cases the physician caring for the patient post-discharge is not the same physician who ordered the screen. In the course of assuring follow-up, investigations reveal other health care providers caring for the newborn/infant with whom the information may be shared. All Newborn Screening test results are made available electronically for every baby screened, to the ordering physician via the submitter (usually the birth hospital, or the hospital to which a baby was transferred and which collected the specimen.) Practices vary between hospitals, resulting in some physicians not receiving the written or electronic results for several weeks. In addition when parent's change their baby's physician, the new physician may not have access to the results from the birth hospital. In other cases the neonatologist or hospitalist or

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another on-call physician will be the ordering physician and will not be following the baby after discharge. These circumstances result in frequent requests to the newborn screening program for results.

As part of the public health surveillance responsibilities, the NNSP staff may share results of screening and follow-up testing with other State's Public Health Newborn Screening Programs for babies who are either born in Nebraska but being treated/followed in another state, or babies born in other states but who are being treated/followed in Nebraska. This will occur via phone and fax.

Exchange of information necessary for the care and treatment of the patient

Phone requests for newborn screening results from physician offices may be accepted. Frequently these are physician offices wishing to verify screening results as part of their standard of care at an early well-baby checkup. Other requests may be because of concern of a physical condition possibly related to a condition for which Nebraska screens newborns and these requests may or may not be during the neonatal or infant period. Program staff will request verbal verification from the requesting physician office, that the patients for whom results are requested are being seen by a physician in that practice. The fax number to which results are sent by the program, will be verified as associated with that practice. For requests from practices outside Nebraska, providers will be instructed to fax the request in writing on office letterhead and verify they are the patient's health care provider. Results sent, will have this verification: documented via cover sheet ("as per your request for your patient").

In 2010 the NCAA passed a guideline for collegiate athletes that they must be tested for sickle cell trait, show proof of a prior test, or sign a waiver releasing an institution from liability if they decline to be tested. The NCAA and NATA indicate that athletes with SCT can participate in college sports but warn of three concerns for athletes: gross hematuria, splenic infarction and exertional rhabdomyolysis "which can be fatal." Increasingly, more sports medicine programs, coaches and athletic trainers have been incorporating sickle cell carrier information as part of the pre-participation physical. This has resulted in increased requests to the program for newborn screening test results, directly from students and their parents. Nebraska did not begin screening for sickle cell disease (and therefore obtain trait status) until November 1, 1996. In order to accommodate these requests the Nebraska Newborn Screening Program will continue to allow physician access as above. When the program is contacted by student athletes or their parents (if a minor) they will be informed that they must have their physician request the results. For these requests the physician must submit a copy of the signed release from the patient or parent (if the patient is a minor) authorizing that physician to treat the patient. Since HIPAA allows us to share protected health information for the purposes of care and treatment of the patient, this release is all that is needed. It may be accompanied by the release of information, but is not required.

When proper documentation of a request is received by the program, a search for the results will be made. If all data elements requested match, results will be sent to the requesting physician. Screening results, confirmatory test results and diagnoses

documentation will be sent as requested. If only screening test results are available, the results will be returned with the disclaimer stating: "The following test results are from a newborn screening test. These results are not diagnostic and this office does not have any other test results to confirm the screen. The patient may wish to consider further testing to confirm or rule out a diagnosis."

Under Nebraska State Statute 84-712.05 the Department has the discretion to NOT release protected health information. The requirement above that information regarding sickle cell trait for athletes be released only to the athlete's physician, is being made because the test results must be interpreted by a physician. The results are in a code not commonly understood by the general public, in order of quantity of type of hemoglobin. So for example a result of "FAS" would be "fetal" hemoglobin in highest quantity, "adult" hemoglobin in the next highest quantity and "sickle" hemoglobin in the lowest quantity. This would be interpreted as a sickle cell trait screening result.

Release of aggregate, non-identifiable information:

Data and numbers may be reported to national databases for reporting program statistics such as the National Newborn Screening and Genetics Resource Center Information System. No patient identifiers may be included.

1. Procedure approved 4/4/11
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